Special Medical Services



New Hampshire 2004 Survey of Parents of Children with Special Health Care Needs Receiving Supplemental Security Income for Their Own Disability

New Hampshire Department of Health and Human Services
Office of Medicaid Business and Policy
Medical Services Bureau
Special Medical Services Section

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Background

New Hampshire Special Medical Services (SMS)¹ is responsible for assuring statewide services to children with special health care needs (CSHCN)² and their families, and for providing data and technical expertise to agencies, medical and service providers, legislators, and parent groups. New Hampshire's state-supported programs for children with special health care needs are guided by the requirements of the Maternal and Child Health Title V Block Grant, which includes National Performance Measures (NPM's) for CSHCN that set forth the standards for the states' efforts. (Figure 1)

Figure 1

The National Performance Measures (NPM'S)

Performance Measure #01: The percent of newborns who are screened and confirmed with condition(s) mandated by their State-sponsored newborn screening programs (e.g. phenylketonuria and hemoglobinopathies) who receive appropriate follow up as defined by their State. **Not measured by the National Survey**

Performance Measure #02: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN Survey)

Performance Measure #03: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)

Performance Measure #04: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (CSHCN Survey)

Performance Measure #05: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)

Performance Measure #06: The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life. (CSHCN Survey)

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¹ New Hampshire Department of Health and Human Services, Office of Medicaid Business and Policy, under authority of RSA 132 (NH Revised Statutes Annotated).

² The federal Maternal and Child Health SMS defines CSHCN as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998; 102:137-140.

A major national survey was designed by our federal partners to provide baseline outcome data for these selected National Performance Measures of the Title V Block Grant. In 2001, the National Survey of Children with Special Health Care Needs³ (hereafter referred to as 'the national survey') was conducted "...to assess the prevalence and impact of special health care needs among children in all 50 States and the District of Columbia." This telephone survey explores the extent to which children with special health care needs have medical homes, adequate health insurance, access to needed services, care coordination, satisfaction with care and impact on the family.

In New Hampshire more than 3,000 households with children were screened in order to identify a sufficient pool of children with special needs. (See Appendix 1 for Survey Screener Criteria) A similar process was used in every state. Each state was guaranteed a sufficient pool of 750 completed interviews. Interviews were conducted with the parents of identified CSHCN.⁴ The national data collection method, referred to as SLAITS (State and Local Area Integrated Telephone Survey), was developed for the Centers for Disease Control and Prevention by the National Center for Health Statistics⁵. The national survey results for New Hampshire will hereafter be referred to as the NH CSHCN survey results.

The national survey estimates the population of CSHCN in the state as 47,059 or 15.1% of children between birth to age 18. This estimate is consistent with the number of children known to meet these criteria in the state. The results from the NH CSHCN survey are meaningful; however, there is a subpopulation of SSI-receiving CSHCN that the national survey was not specifically designed to capture. For instance, in New Hampshire, the national survey revealed that of those surveyed, only seventeen (unweighted number) CSHCN receiving **Supplemental Security Income** (SSI)⁶ for their own disability were identified.

The New Hampshire Survey of CSHCN Receiving SSI

Because the national survey was not designed to estimate the New Hampshire population of CSHCN receiving SSI, in order to determine how SSI-receiving CSHCN score on the national outcome criteria, New Hampshire's Special Medical Services in 2004 conducted its own survey, the New Hampshire Survey of Parents of Children of Special Health Care Needs Receiving SSI for Their Own Disability, hereafter referred to as 'the NH SSI CSHCN survey'. (See Appendix 2 for the NH SSI CSHCN survey instrument) Because eligibility for SSI requires both means testing and meeting specific diagnostic criteria, it is important to have an accurate picture of the needs of this population

³ van Dyck PC, McPherson M, Strickland BB, Nesseler K, Blumberg SJ, Cyamon ML, Newacheck PW. The National Survey of Children with Special Health Care Needs. Ambulatory Pediatrics 2:29-37. 2002.

⁴ http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm

⁵ Data source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001. Version: Revised sampling weights, version 2. Analysis Date: April 28, 2003.

⁶ Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind, and disabled people, who have little or no income, and it provides cash to meet basic needs for food, clothing, and shelter. http://www.ssa.gov/notices/supplemental-security-income/

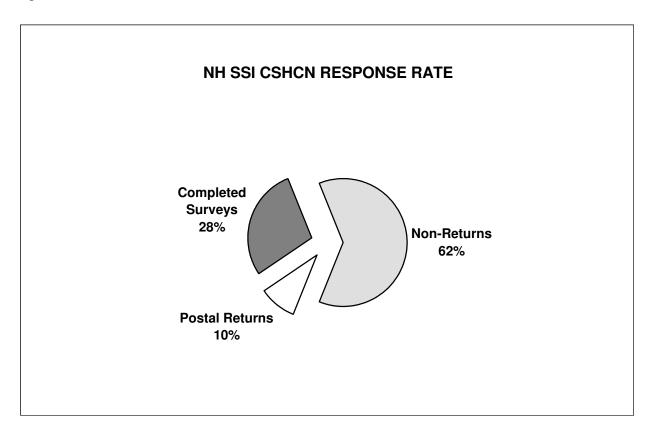
to guide strategic planning for the Title V program.

The New Hampshire SSI CSHCN survey employed an instrument that mirrored the national survey questions used to determine the success rate of the five core outcomes that are correlated with five National Performance Measures in the Title V Maternal and Child Health Block Grant requirements.

Survey Response

In October 2004, 1141 surveys were mailed to the addresses of the known population of SSI-receiving children with special health care needs, birth to age 18, who were residing in the state during the preceding twelve months. Of the 1141 mailed surveys, 108 (9%) were returned as non-deliverable, while 291 (26%) were returned and completed. There was no response from 742 (72%) delivered addresses. After removing the non-deliverable surveys, a final response rate of 28% was achieved. (Figure 2) With such a low response rate, it is understood that the survey findings are influenced by nonresponse *bias* and the reader should keep this in mind.⁷

Figure 2



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⁷ Hager, Mark A., et al. (2003). Response Rates for Mail Surveys of Nonprofit Organizations: A Review and Empirical Test. Nonprofit and Voluntary Sector Quarterly, vol.32, no. 2, 252-267.

It must be emphasized that the NH Survey is not intended to be a scientific research effort; rather, the intent is to inform program planning. The rigorous criteria necessary to assure research-level results were not feasible for this project. Given the difficulty in reaching this population, the 'best practices' commonly utilized to maximize the potential for a high survey response rate were also outside the scope and budget of the project. No claims are made from the results regarding the characteristics of the nonresponders and/or the general population of SSI-receiving CSHCN. However, the findings from this survey do offer greater insight into the needs of the respondents and serve as the most reliable and available information regarding this group of NH CSHCN.

Methodological Differences Between the National Survey and the New Hampshire Survey

One of the obvious differences between the NH SSI CSHCN survey and national NH CSHCN survey is that the national survey is a population-based telephone survey that allows the findings to be generalized to the entire population of CSHCN, while New Hampshire's survey can only speak to those who chose to respond to the survey, which was mailed to a known group. Additionally, the SLAITS sampling method was designed to estimate NH children known to have special health care needs, while the NH SSI survey was designed to survey all known families with CSHCN who receive SSI for their own disability.

Core Outcomes

Both the NH CSHCN and the NH SSI CSHCN surveys will be used to address the success rate that supports the national performance measures. Two primary resources were used in the development of this report, which utilizes the data to bring into closer focus the health care status of the SSI-receiving group of CSHCN. Data from the national survey is drawn from SLAITS files⁸ and from the Data Resource Center for CSHCN⁹. The NH SSI CSHCN survey was analyzed by the NH Department of Health and Human Services¹⁰. If the complexity of the process rendered slight variations in a figure, the figure from the Data Resource Center was used.

Figure 3 illustrates how the NH SSI CSHCN survey results contribute to the current outcome data for New Hampshire children with special health care needs. Progress on the NPM's is measured by Core Outcomes, which require multiple criteria to meet the threshold for "success". Only those responses that meet the success criteria are incorporated in the results for the core outcomes. The five core outcomes and the results from the national survey for the United States, the national survey for New Hampshire CSHCN, and the NH SSI CSHCN survey are included in Table 1.

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⁸ Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001. Version: Revised sampling weights, version 2. Analysis Date: April 28, 2003.

⁹ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2001*. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.

¹⁰ Office of Medicaid Business and Policy, Bureau of Healthcare Research.

Figure 3

Title V Maternal and Child Health: CSHCN Measures and Outcomes

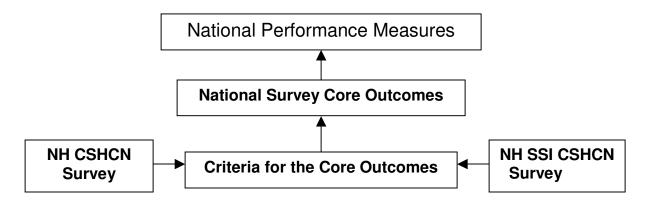


Table 1

Core Outcomes for National Performance Measures for CSHCN	NATIONAL Survey Success Rate	NH CSHCN Survey Success Rate	NH SSI Survey Success Rate
Families of CSHCN will partner in decision-	58%	55%	49%
making and will be satisfied with the services	CI	CI	CI
they receive.	(56.5 – 59.5)	(47.6 – 62.4)	(43.2 – 54.7)
CSHCN will receive coordinated ongoing comprehensive care within a medical home.	53%	56%	14%
	CI	CI	CI
	(52.0 – 53.9)	(51.3 – 60.7)	(10.0-17.9)
Families of CSHCN will have adequate private and/or public insurance to pay for the services they need.	60%	62%	33%
	CI	CI	CI
	(59.0 – 60.9)	(57.3 – 66.7)	(27.5 – 38.43)
Community-based service systems will be organized so families can use them easily.	74%	78%	53%
	CI	CI	CI
	(72.7 – 75.3)	(72.0 – 84.0)	(47.2 – 58.7)
Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.	6% CI (5.7 – 6.3)	3% ¹¹ CI (0.02 – 6.4)	4% ¹² CI (0.6 – 7.3)

CI: There is a 95 percent chance that the true value falls within these boundaries.

 11 Estimates do not meet the National Center for Health Statistics standard for reliability or precision. The relative standard error is greater than 30%.

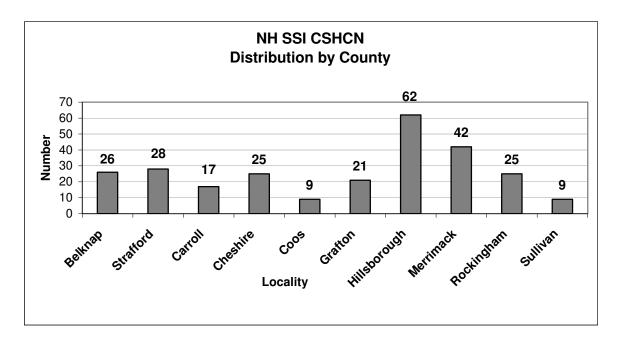
¹² Estimates do not meet the National Center for Health Statistics standard for reliability or precision. The relative standard error is greater than 30%.

The Core Outcomes for the above NPM's are calculated based on the number of respondents who consistently answered favorably to **all items** needed to constitute the outcome. The findings of the NH SSI CSHCN survey reflect New Hampshire's success rate in addressing the needs of CSHCN that are receiving SSI for their own disability. There are clear disparities between the overall NH CSHCN population and the SSI population.

Demographics

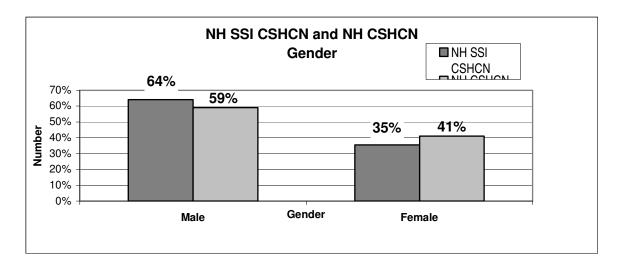
All ten New Hampshire counties were represented in the NH SSI CSHCN 2004 survey. The most populous, Hillsborough County, accounted for 24% (n=62) of the respondents, followed by Merrimack at 16% (n=42), Strafford at 11% (n=28) and Belknap at 10% (n=26). The remaining counties were Rockingham (10%), Cheshire (10%), Grafton (8%), Carroll (6%), Sullivan (3%), and Coos (3%). (Figure 4)

Figure 4



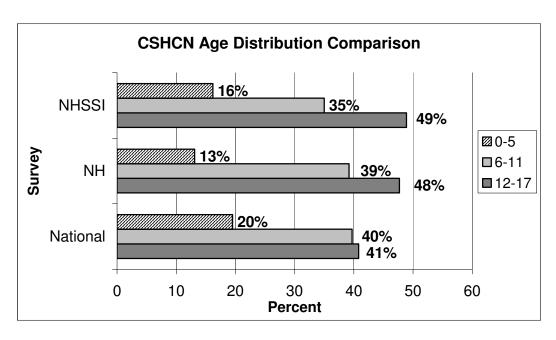
Of the 253 reports of gender in the NH SSI survey, 64% are male and 35% are female. The National survey sample for New Hampshire estimates a distribution of 59% male and 41% female. (Figure 5)

Figure 5



The age distribution of the children represented by the NH CSHCN-SSI survey, the national survey data for NH CSHCN, and the national survey for U.S. CSHCN, is illustrated in Figure 6.

Figure 6

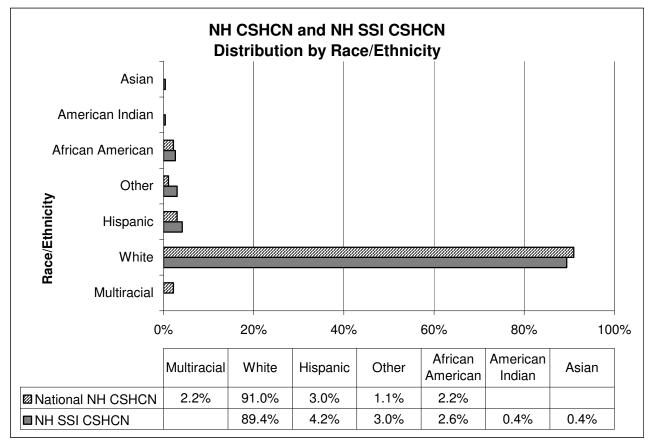


The population of New Hampshire children under age 18 is primarily White $(95\%^{13})$. The NH CSHCN SSI survey population is 89% White, which is somewhat more diverse than the national survey for NH CSHCN indicates. (Figure 7)

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¹³ US Census 2000

Figure 7



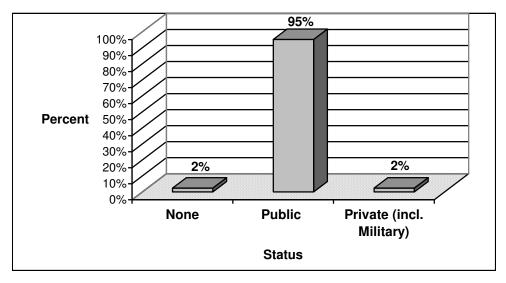
Note: Use caution in interpreting Race/Ethnicity when cell size is less than 5%.

New Hampshire is significantly less racially/ethnically diverse than most other states in the nation; however, minority and immigrant populations are now increasing in the southern-most area of the state. As the minority and refugee populations increase in New Hampshire, service providers for children with special health care needs are proactively integrating culturally sensitive and culturally competent methods into their practice sites. For example, Special Medical Services allocates designated funds to support foreign language interpreters for the Child Development Clinic site. The Department of Health and Human Services provides and facilitates interpreter services for the public seeking services or information. The NH Hospital Association members utilize the AT&T Language Line, and there are initiatives in place with the Endowment for Health and the NH Minority Health Coalition.

The health insurance coverage rate for all NH CSHCN, per the national survey, is 95%. According to the national survey results for New Hampshire, however, 28% of currently insured CSHCN have insurance that is not adequate to their needs. Of 249 NH SSI CSHCN survey respondents that indicated insurance status, 95% were currently covered by insurance, and 81% had insurance that met the child's needs. (Figure 8) Medicaid accounts for 84% of the insurance by type for the SSI CSHCN population.

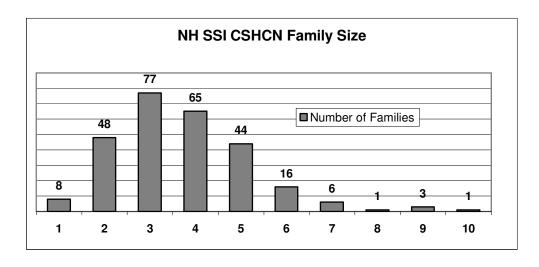
Figure 8





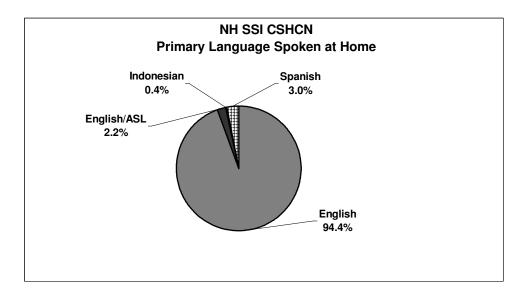
The majority of families of CSHCN receiving SSI for their own disability averaged three members per family, followed by four members and two members per family, respectively. (Figure 9)

Figure 9



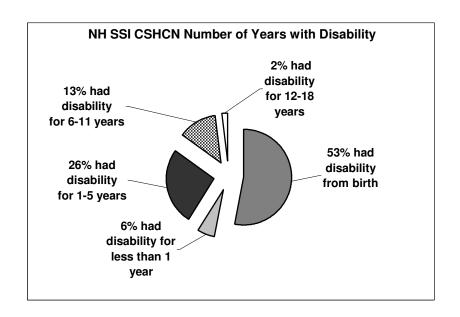
English is reported as the primary language spoken in the homes of the majority of survey respondents, followed by Spanish and American Sign Language. (Figure 10)

Figure 10



Over 50% of children referenced in the survey had the disability from birth. The next longest duration, between one and six years, was reported by over 25% of respondents. (Figure 11)

Figure 11¹⁴



¹⁴ Number of Years with Disability = Age – How long child had primary condition

Access and Impact

The NH SSI CSHCN survey addressed the same key domains as the national survey: medical homes, adequate health insurance, access to needed services, care coordination, satisfaction with care and impact on the family.

The NH CSHCN survey and the NH SSI CSHCN survey report data specific to the federally selected sub-questions that make up the five core outcomes. To meet the threshold for 'success' as a core outcome, the respondent had to answer "always" or "usually" to <u>all</u> the sub-questions comprising the core outcome. Table 2 below shows the results for both New Hampshire surveys.

Table 2

New Hampshire Core Outcomes (NH CSHCN and NH SSI CSHCN)

Survey	NH CSH Valid Number	CN %	NH SSI Valid	CSHCN
Criteria ¹⁵	(or *Weighted Number)	Yes ¹⁶	Number	Yes
1. Families of CSHCN will partner in decision- making and will be satisfied with the services they receive.	296	55%	142	49%
1.1 Doctors usually or always made the family feel like a partner	272	86%	242	83%
1.2 Family was very satisfied with services received	279	58%	149	51%
2. CSHCN will receive coordinated ongoing comprehensive care within a medical home.	718	56%	40	14%
2.1 The child had a usual source of care 2.1a The child had a usual source for sick care	43* 43*	92% 92%	260 267	89% 92%
2.1b The child had a usual source for preventive care	47*	100%	276	96%
2.2 The child had a personal doctor or nurse	43*	93%	265	92%
2.3 The child had no problems obtaining referrals when needed	19*	77%	208	73%
2.4 Effective care coordination was received when needed	3*	37%	55	18.9%

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¹⁵ Criteria are MCH-defined Core Outcomes for National Performance Measures for CSHCN; data source for the Core Outcomes is "Progress Toward Implementing Community-Based Systems of Services for Children with Special Health Care Needs: Summary Tables from the National Survey of Children with Special Health Care Needs, 2001"; data release April 28, 2003, Tables 1 through 10.

¹⁶ In order to be counted as a "yes (success)" in the Core Outcome row (the overall percentage) ALL of the components must have been answered "always or usually" by the individual respondents. Because the same respondents do not answer the same way for each item, the final percentage for all respondents is almost always lower than any given item, and can never be higher than the lowest item.

Survey Criteria ¹⁵	NH CSH Valid Number (or *Weighted Number)	CN % Yes ¹⁶	NH SSI Valid Number	CSHCN % Yes
2.4a The child had professional care coordination when needed	5*	78%	166	58%
2.4b Doctors communicated well with each other (excellent/very good)	4*	62%	144	51%
2.4c Doctors communicated well with other programs (excellent/very good)	3*	49%	120	42%
2.5 The child received family-centered care	31*	71%	167	57.4%
2.5a Doctors usually or always spent enough time	39*	88%	222	78%
2.5b Doctors usually or always listened carefully	41*	91%	242	85%
2.5c Doctors were usually or always sensitive to values and customs	40*	90%	227	81%
2.5d Doctors usually or always provided needed information	37*	84%	222	78%
2.5e Doctors usually or always made family feel like a partner	39*	88%	242	84%
3. Families of CSHCN will have adequate private and/or public insurance to pay for the services they need.	727	62%	97	33%
3.1 Child had public or private insurance at time of interview	44*	94%	282	98%
3.2 Child had no gaps in coverage during year prior to the interview	40*	85%	233	84%
3.3 Insurance usually or always met child's needs	39*	89%	228	81%
3.4 Costs not covered by insurance were usually or always reasonable	32*	76%	123	45%
3.5 Insurance usually or always permitted child to see needed providers	41*	93%	241	86%
4. Community-based service systems will be organized so families can use them easily.	274	78%	153	53%
4.1 Services were usually or always organized for easy use	271	78%	153	53%
5. Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence. ¹⁷	108 ¹⁸	3%	5 ¹⁹	4%

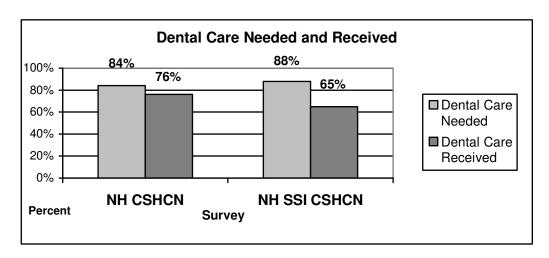
Estimates do not meet the NCHS standard for reliability or precision.
 Estimates are based on data from National Survey of CSHCN interviews conducted after July 5, 2001 (less than the full survey period).
 Small total response decreases reliability

Survey	NH CSHCN NH S			H SSI CSHCN	
Criteria ¹⁵	Valid Number (or *Weighted Number)	% Yes¹ ⁶	Valid Number	% Yes	
5.1 Child has received guidance and support in transition to adulthood	108	13%	14	4.8%	
5.1a Doctors have talked about changing needs as child becomes an adult	110	52%	55	44%	
5.1b Child has plan for addressing changing needs	57	67%	35	29%	
5.1c Doctors discussed shift to adult provider 5.2 Child has received vocational or career training	57 113	41% 17%	21 26	18% 22%	

An extensive number of additional questions relating to the need for, and receiving of, specialty services were asked in the national survey. These items are associated with Core Outcome 2 (comprehensive care in a medical home), under Question 2.3, regarding the difficulty obtaining referrals when needed. For the purpose of the abbreviated NH SSI CSHCN survey, inquiries were made regarding two specialty areas; i.e. dental care and mental health needs.

NH children receiving Medicaid, which includes the majority of the SSI CSHCN group, receive dental services solely through providers that accept Medicaid. The Medicaid payments for many dental procedures were increased two years ago; however, there is both a shortage of dentists in the state, generally, and a shortage of those that accept Medicaid. (Figure 12)

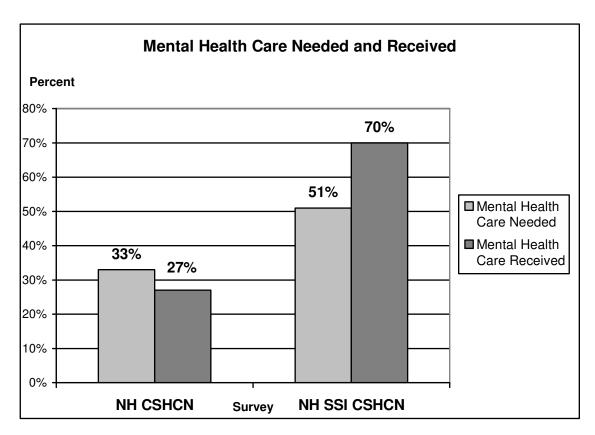
Figure 12



While one third of the NH CSHCN reported needing mental health services, and half of the SSI group reported that need, only 27% of the NH CSHCN reported receiving the mental health care needed, while 70% of the SSI group reported receiving the needed services. (Figure 13) One question that emerges from this data is whether the SSI group reporting the need for mental health care is receiving this specialty care in a greater proportion than non-SSI CSHCN, due to

the prevalence of the diagnosis of Serious Emotional Disturbance (SED) in the SSI population. A lesser degree of severity of mental health issues, which does not meet the restrictive diagnostic criteria for SSI eligibility, is more likely to be the case among the non-SSI group. Physicians are often reluctant to 'label' a child SED, and many serious behavioral and mental health conditions do not meet the threshold for SSI eligibility. The need for mental health services for CSHCN and the difficulty locating and/or accessing such services, especially for those without an SED-related diagnosis, has emerged as a priority in the New Hampshire "Assessing Needs and Resources for Children with Special Health Care Needs" (Delphi survey) which is also included as part of the Five Year Needs Assessment.

Figure 13



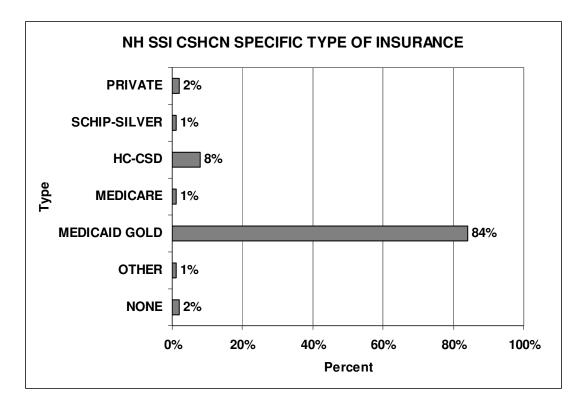
As reported previously, 95% of the 249 families that responded to the questions about health insurance coverage reported having coverage for their child at the time of interview/survey. Figure 14 details the type of insurance held, with the majority being covered by some form of public insurance, such as Medicaid. New Hampshire is one of 19 states that do not use Federal SSI eligibility for automatic Medicaid eligibility, and one of 11 states ("§209(b) states") that use at least one Medicaid criterion that is more restrictive than the SSI program. Despite the requirement that disabled children must file separate applications for SSI and Medicaid, approximately 70% of New Hampshire children receiving SSI for their own disability also are

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²⁰ Benefits Planning Query Handbook, Social Security Administration, September 2004

insured through Medicaid.²¹ Of those whose parents responded to the survey, 95% are covered by some form of Medicaid or Medicare for their health care needs. Federal and state discussions regarding Medicaid reform, or modernization, primarily propose measures for cost sharing utilizing a combination of reduced benefits and increased out-of-pocket expenses. This is of heightened concern for the youth with special health care needs (YSHCN) receiving SSI and Medicaid, who are aging out of pediatric services and transitioning to adult status.

Figure 14



In addition to insurance status, the NH SSI CSHCN survey asked parents about their out of pocket expenses related to medical care for their child, the amount of time family members spent on providing health care for their child at home, the amount of time the family spent coordinating care and services for their child, and the affect of the child's condition and needs on income and working status. Out of pocket expenses for the child's medical care were reported in both the national and NH SSI CSHCN surveys. Many families sustained costs exceeding \$500, up to over \$1000 per year. (Figure 15 and Figure 16) A recent study finds that health care cost-sharing has more impact on low-income people, as Medicaid beneficiaries pay a proportionately larger share of their income for out-of-pocket medical expenses; in 2002, poor disabled SSI beneficiaries covered by Medicaid, including YSHCN over age 18, spent an average of 6% of

²¹ Special Medical Services, Bureau of Medical Services, Office of Medicaid Business and Policy, NH Department of Health and Human Services, 2004.

their income, more than eight times the percentage of income paid by non-low-income adults with private insurance. 22

Figure 15

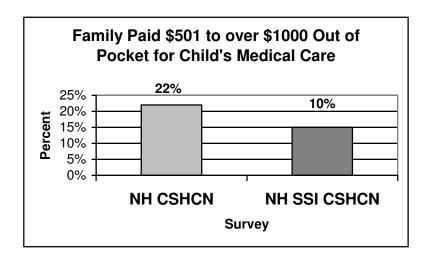
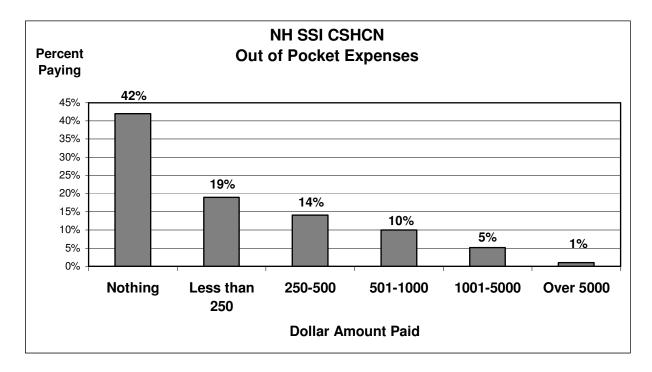


Figure 16



²² Out-of-Pocket Medical Expenses for Medicaid Beneficiaries are Substantial and Growing, Leighton Ku and Matthew Broaddus, Center on Budget and Policy Priorities, May 2005.

Over two-thirds of the families of NH SSI CSHCN surveyed reported that they provide health care for their child at home. (Figure 17 and Figure 18) These families experience the impacts of both a financial affect as well as the affect of often 'around-the-clock' health care for a disabled child. Children who qualify for SSI for their own disability are by definition experiencing debilitating, and often medically severe problems as a result of their condition. In an article authored by SMS staff, currently in press for the Journal of Maternal and Child Health²³, an analysis of selected national survey NH data indicated that the severity of the child's condition had a more profound affect on the family than simply the presence or lack of financial resources.

Figure 17

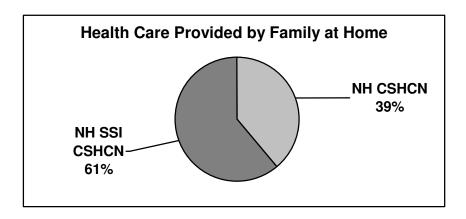
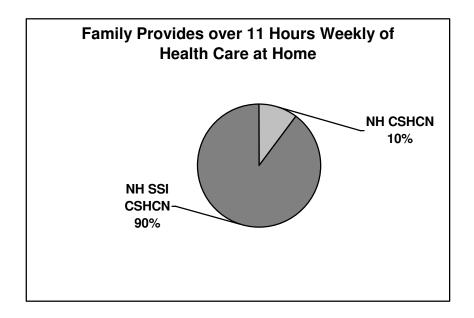


Figure 18



²³ Economic Impact on Families Caring for Children with Special Health Care Needs in New Hampshire: The Effect of Socioeconomic and Health-Related Factors. Bumbalo, J., Ustinich, L. Ramcharran, D., and Schwalberg, R., Maternal and Child Health Journal Vol. 9S, No. 2, June 2005 DOI: 10:1007/s10995-005-4350-3

In addition to families often providing direct health care for their child, the various components of arranging for coordination of care among providers, programs and services is also a task that is undertaken by almost half of families of children with special health care needs, including the families of the NH SSI CSHCN surveyed. (Figure 19) The data also indicate that parents of CSHCN receiving SSI must provide a significantly higher percentage of their own care coordination than other NH families with CSHCN. (Figure 20) Only 18.9% reported that they received effective care coordination when needed (Table 2).

Figure 19

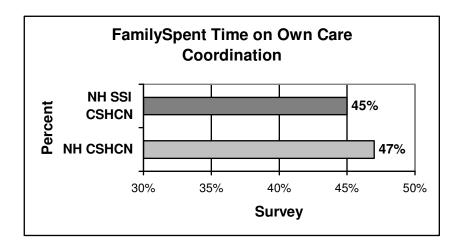
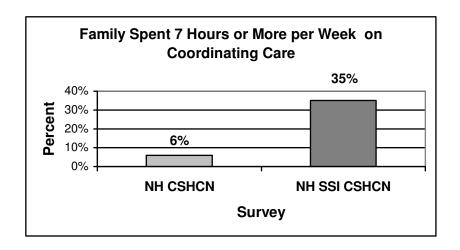
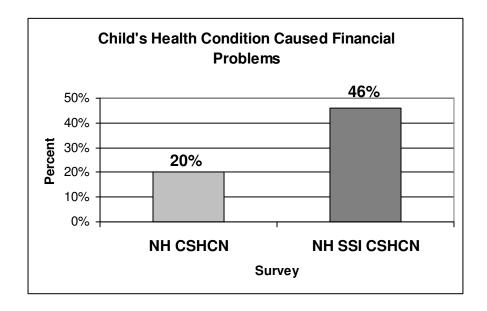


Figure 20



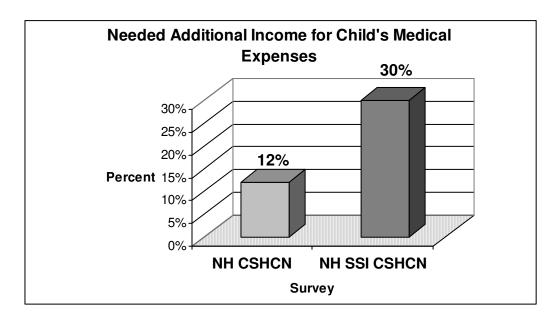
Over 45% of families of SSI-receiving CSHCN report sustaining financial problems because of the child's health condition, which is more than double the percentage reported in the national survey by families of CSHCN in New Hampshire. (Figure 21)

Figure 21



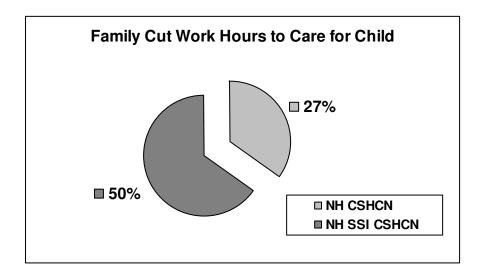
Parents of children receiving SSI for their own disability report a significantly higher need for additional income to pay for health care/medical expenses not covered by insurance. (Figure 22)

Figure 22



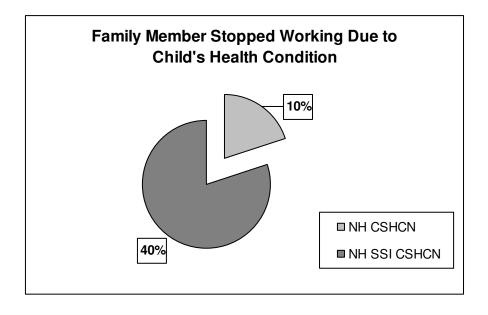
In addition, half of the families of the CSHCN SSI group reported having to cut work hours to care for their child. Slightly less than 30% of the NH CSHCN group reported having to decrease work hours. (Figure 23)

Figure 23



The data analyzed for the Maternal and Child Health Journal article indicate that it is the severity of the child's condition that most impacts the family with regard to situations such as having to reduce hours worked in order to provide care in the home, or the need to stop working altogether to care for the child, due to the child's condition.²⁴

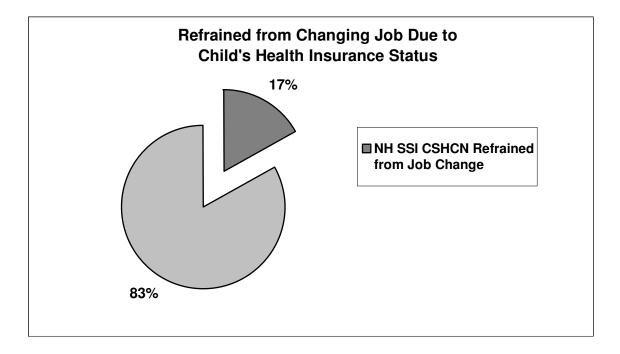
Figure 24



²⁴ Ibid. Bumbalo et.al. (2005).

The NH SSI CSHCN survey asked families to respond to one question that was not asked on the national SLAITS survey: "Have you or other family members refrained from changing jobs because of your child's health insurance status?" (Figure 25) Based on response to this inquiry, New Hampshire Special Medical Services has suggested that this item be included in the next iteration of the national survey, scheduled to be conducted in 2006.

Figure 25



Transition to Adult Life

Questions regarding the transition to adult life and adult services were added to the national SLAITS survey after the survey was initially begun. For this reason, the NH data is limited and is not intended to represent the current, largely unknown, status of transition efforts and measured outcomes in the state. When the national survey is repeated next calendar year, the transition questions will be included from the beginning, and will be asked of all interviewees representing CSHCN age 12 or older. The NH SSI CSHCN survey asked the transition questions of all families with SSI-receiving CSHCN, age 12 to 18. (Table 3) The numbers of people responding to the transition questions ranged from 124 to 127, or approximately 43% of all respondents.

Two items of significance have emerged from the NH SSI survey data: 1) this group of children are much less likely to have plans to address their changing needs developed with their physicians, and 2) the physicians and nurses treating the SSI group of CSHCN are less likely to discuss transition to an adult medical practitioner. (Table 3)

Table 3

TRANSITION PLANNING (Percent of 'yes' responses)			
NH CSHCN Survey NH SSI CSHCN Survey			
1. If child is 12 years or older, has the child's do	1. If child is 12 years or older, has the child's doctor talked with family or child about how		
health care needs might change when he/she bec	omes an adult.		
51%	44%		
2. Has a plan for addressing these changing needs been developed with the doctor or other			
health care providers?			
66% 29%			
3. Has the child's doctor or other health care provider discussed having the child eventually see			
a doctor who treats adults?			
40%	18%		
4. Has the child received any vocational or career training to help him/her prepare for a job			
when he/she becomes an adult?			
17%	22%		

Conclusions

The analysis of the survey data regarding this subpopulation of CSHCN in New Hampshire indicates several issues for consideration in future policy and program planning. These findings include the following:

NH CSHCN receiving SSI for their own disability demonstrate a greater need for care coordination than NH CSHCN in general.

The SSI CSHCN population evidences a greater need for better-organized community-based systems.

Respondents express a desire for increased access to public/private funding, perhaps because of a concern regarding costs that are not covered by insurance.

Although almost 98% of the sample are insured and an almost equally high percent are insured through Medicaid, respondents perceive that this coverage alone is not sufficient to meet the dental and mental health care needs of children receiving SSI. It is unknown from the survey data what the perceived insufficiencies might be.

The adequacy of Medicaid appears to be an issue for families that must pay out-of-pocket for non-covered medical and health care-related items and services, perhaps for durable medical equipment or psychotropic medications not included in the state formulary.

The well-documented shortage of dental providers in New Hampshire, and the further shortage of those who will accept Medicaid, reflects the need for the State to support initiatives to increase the number of providers who will accept Medicaid clients, including CSHCN.

Survey results related to the need to curtail employment and the intensity of at-home care indicate a need for increased respite care at home, and child care services, for these medically and/or behaviorally complex children.

Youth with special health care needs age 12 and older are much less likely to have plans to address their changing needs developed with their physicians; professionals treating the SSI group of CSHCN are less likely to discuss the transition to a medical practitioner who treats adults. Both of these issues need to be addressed.

In summary, the overall results of the NH SSI CSHCN survey indicate that this group of children and their families experience an array of health-related difficulties, which may have a more severe impact on the family than the impact of difficulties experienced by families of NH CSHCN in general. The medical and financial eligibility requirements for SSI benefits are sufficiently restrictive to assure that the children receiving Supplemental Security Income for their own disability are, by definition, in a heightened state of need for this assistance.

The survey also indicates that the provision of SSI does not close the gap between what Medicaid will cover and what families must pay for out-of-pocket. Meeting the actual expenses of the child's care is often accomplished by working multiple jobs and/or providing a high degree of health-related care in the home. It appears that the cost-of-care burden is greater for these families than for the families of NH CSHCN in general. Furthermore, respondents indicate concerns regarding adequacy of insurance coverage. The survey was not designed to capture further details about the issues that elicited respondent concerns. SMS plans a second mailing to the families of CSHCN receiving SSI, to request additional feedback on the issues raised. This process will be confidential and anonymous, used only to extract data for planning purposes, as was the original survey.

The NH survey also indicates that these children are evidencing a greater need for comprehensive, community-based, care coordination and well-organized service systems. Details for this initiative are outlined under National Performance #3 in the 2006 Title V Block Grant narrative. Specific deficits are indicated in the areas of mental health services and the transition to adult services. Special Medical Services is currently working on a special grantfunded project²⁵ to meet the needs related to transition to adult care for CSHCN.

Given that the majority of children receiving SSI for their own disability will continue to meet the financial and medical criteria for this assistance, it appears imperative that New Hampshire's programs for CSHCN specifically and pro-actively address the unique needs of this subpopulation, as they age into adulthood.

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²⁵ New Hampshire Youth Health Care Transition Project, funded by the Champions for Progress Incentive Award, Champions for Progress Center, Early Intervention Research Institute, Utah State University.

APPENDICES

- Survey Screener Criteria for CSHCN
 The New Hampshire Survey of Parents of Children with Special Health Care Needs Receiving SSI for Their Own Disability, 2004.

Appendix 1: Survey Screener Criteria for CSHCN

The Children with Special Health Care Needs (CSHCN) Screener© was developed through the efforts of the Child and Adolescent Health Measurement Initiative (CAHMI), a national collaboration coordinated by FACCT—The Foundation for Accountability. The Screener is a set of five consequences-based questions used to identify children with chronic or special health care needs. The questions are designed to be self-administered or telephone administered as part of a parent/caretaker survey.

Screening Criteria

The theoretical framework used by the CSHCN Screener is based on the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) (Stein, et al., 1997). Like the QuICCC, the criteria used by the CSHCN Screener to determine whether a child has a chronic or special health care need are independent of a specific diagnostic or a formally recorded etiology. The CSHCN Screener uses health-related consequences to identify children with chronic or special health care needs. The following must all be present for a child to qualify:

- The child must currently experience a specific consequence.
- The consequence is due to a medical, behavioral, or other health condition.
- The duration or expected duration of the condition is 12 months or longer.

The first part of CSHCN Screener question asks whether a child experiences one of five different health consequences:

- Use or need of prescription medication
- Above average use or need of medical, mental health or educational services
- Functional limitations compared with others of same age
- Use or need of specialized therapies (OT, PT, speech, etc.)
- Treatment or counseling for emotional, behavioral or developmental problems

The second and third parts of each question ask those responding "yes" to Part 1 of the question whether the consequence is due to a specific health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

All three parts of at least one screener question (or in the case of question 5 there are two parts) must be answered "yes" for a child to meet the CSHCN Screener criteria for having a chronic condition.

The CSHCN Screener has three "definitional domains". They are:

- Dependency on prescription medications
- Service use above that considered usual or routine
- Functional limitations

The definitional domains are not mutually exclusive categories. A child identified by the CSHCN Screener may quality on one or more domains.

Appendix 2: Survey



State of New Hampshire
Department of Health and Human Services
Office of Medicaid Business and Policy
Special Medical Services Bureau

29 Hazen Drive Concord, NH 03301-6504 1-800-852-3345 Ext. 4488 * Fax 603-271-4902 * TDD 1-800-735-2964

Insurance/Cost-of-Care Survey for Children with Special Health Care Needs, 2004

INTRODUCTION

The Special Medical Services Bureau is conducting this survey to gather accurate information about the cost of health care and the impact on children and youth with special health care needs and their families. We are sending this survey to families whose child with special health care needs is receiving SSI (Supplemental Security Income) for his or her own condition.

This survey is anonymous and confidential. No names or individual identification are used. The survey will only compile data based on numbers and percentages that result from the survey.

We report the results to the federal Maternal and Child Health Bureau, which provides funding for state programs serving children with special health care needs, under Title V of the Social Security Act. More importantly, the results are used to help the Special Medical Services Bureau make policy and funding decisions that are designed to improve services statewide.

Please take a few moments to look over the survey. If you decide to participate, please fill out the entire survey. We will have a better understanding of the cost-of-care issues for families with children with special health care needs if people participate and complete the whole survey.

The survey is very simple and should not take a lot of time. All you have to do is put a check mark in the answer box you select, for each item, and mail the survey back in the postage-paid envelope provided. Please mail it back to DHHS-SMSB, 29 Hazen Drive, Concord, NH 03301-6504, attn: Lee Ustinich, no later than a week after receipt. You may also fax the completed survey to 603-271-4902, Attn: Lee Ustinich. Feel free to call or e-mail with any questions or comments, 603-271-4014. lustinich@dhhs.state.nh.us

Appendix 2: Survey

Thank you very much for your time.

Decision-Making Partner	4. Is there a place that your child usually goes to for routine or preventative care?Yes (1)
We are interested in your role as a partner in the decision making process, along with your child's health care providers. Please choose the answer that best reflects	There is not place (2) There is more than one place (3) Don't know (5)
your experience.	5. Do you have one person who you think of as your child's personal doctor or nurse?
1. In the past 12 months, how often did your child's doctors or other health care providers help you feel like a partner in (his/her) care?	Yes (1) No (2) Don't know (5) In the past 12 months, how much of a
Never (1)Sometimes (2)Usually (3)Always (4)Don't know (5)	problem, if any, was it to get a referral to a specialist who your child needed to see? A big problem (1) A small problem (2) Not a problem (3) Child did not need to see a specialist in
2. Thinking about your child's health needs and the services (he/she) receives, how satisfied or dissatisfied are you with those services?	the past 12 months (4)Don't need referrals (6)Don't know (5)
Very satisfied (1)Somewhat satisfied (2)Somewhat dissatisfied (3)Very dissatisfied (4)Don't know (5)	7. During the past 12 months, was there any time when your child needed coordination among different health care providers and services? Yes (1) No (skip to question 9.) (2) Don't know (skip to question 9) (5)
Medical Home We now would like to ask you about the coordination of services and health care for your child. Please choose the answer that best reflects your experience.	8. If yes , did your child receive all the professional care coordination that was needed? Yes (1) No (2) Don't know (5)
3. Is there a place that your child usually goes to when he/she is sick? Yes (1) There is not place (2) There is more than one place (3) Don't know (5)	9. How well do you think your child's doctors and other health care providers communicate with each other about your child's care?Excellent (1)Very good (2)Good (3)Fair (4)Poor (6)Communication not needed (7)Don't know (5)

Appendix 2: Surve	Apr	endi	x 2: S	Surve
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10. How well do you think your child's doctors and other health care providers communicate with his or her school, early prevention prograchildcare providers, or vocational rehabilitation program?	ms,	Good (3))F nication no	Very goo air (4) t needed (7)	Poor (6)
Check the box that most closely reflects	Never	Sometimes	Usually	Always	Don't
your experience.	(1)	(2)	(3)	(4)	know (5)
11. In the past 12 months, how often did your child's doctor or other health care providers spend enough time with him/her?					
12. In the past 12 months, how often did your child's doctor or other health care provider listen carefully to you?					
13. In the past 12 months, how often were the doctors or other health care providers sensitive to your family's values and customs?					
14. Information about a child's health care can include things such as the causes of any health problems, how to care for the child now, and what changes to expect in the future. In the past 12 months, how often did you get the specific information you needed from your child's doctors and other health care providers?					
Adequate Health Insurance We would like to ask you about health care		Single se escriptions) (9) her:)	(dental, visio	on, (10)
coverage for your child.					
Please choose the answer that best reflects your experience.					
15. What kind of health insurance does your child currently have? No coverage (skip to question 20) (1) Medicaid (Healthy Kids Gold) (2) Medicare (3) HC-CSD (Home Care for Children with Severe Disabilities/"Katie Becket") (4) SCHIP (Healthy Kids Silver) (5) Medigap (6) Military (7)	l be wa 17 ins	is. If your child then any time in the as not covered to yes (1) the covered to you believe this or her responsible. Never (1) the cover (1) the covered to your time.	the past 1 by any he bw (5) ve that you benefits or needs?) es (2)	2 months the alth insuran North Insuran Nort	at your child ce? lo (2) alth
Private health insurance (8)		Usually (; Always (4	,		

Appendix 2: Survey	
Don't know (5)	Impact on the Family
18. Are the costs not covered by your child's health insurance reasonable?Never (1)Sometimes (2)Usually (3)Always (4)	We would like to ask you about the impact of your child's cost-of-care on your family. Please choose the answer that best reflects your experience.
Don't know (5)	22. How much did your family pay out-of-pocket for your child's health care needs in the past 12 months? Important: do not count the cost of insurance itself or any reimbursement from insurance. Out-of-pocket payments for health-related needs include things such as co-pays, non-covered prescription medications, over-the-counter medicines, special foods, adaptive clothing,
19. Does your child's health insurance allow him or her to see the health care providers he or she needs? Never (1)Sometimes (2)	durable equipment, home modifications, any kind of non-covered therapy, and other items or services that are necessary for your child's health care that you must pay for yourself.
Usually (3)Always (4)Don't know (5)	Nothing \$0 (1)S250-\$500 (3) \$501-\$1000 (4)
20. If your child has no public or private health insurance, what is the reason? Please check all that apply.	\$1001-\$5000 (6) Over \$5000 (7) Don't know (5)
Cost too much (1) Not eligible for State insurance (Healthy Kids, Gold/Silver) (2) Do not know about State insurance (Healthy Kids Gold/Silver) (3) Insurance is not in effect yet, pending (4) Don't know (5)	23. Do you or other family members provide health care at home for your child, such as changing bandages, care of feeding or breathing equipment, giving medication and therapies, and providing transportation to appointments? Yes (1)
If you do not know about Healthy Kids Gold or Healthy Kids Silver, may we contact you about this State Insurance option? Yes (1): PhoneNo (2)	No (skip to question 25) (2) Don't know (skip to question 25) (5) 24. How many hours per week do you or other family members spend providing this kind of care?
21. At this time, is your child enrolled in Special Medical Services, the NH Title V program? Yes (1) No (2) Don't know (5)	Hours per weekDon't know (999) 25. How many hours per week do you or other family members spend arranging or coordinating your child's care? This includes making

Appendix 2: Survey

appointments, making sure that care providers are	Don't know (5)
exchanging information, and following up on your child's care needs.	Access to Selected Services
Hours Per Week Don't Know (5) Has your child's health condition(s) caused financial problems for your family? Yes (1)	32. During the past 12 months, was there a time when your child needed dental care, including check-ups? Yes (1) No (skip to question 34) (2) Don't know (skip to question 34) (5)
No (2)No (2)Don't know (5) 27. Have you or other family members cut down on the hours you work to care for your child?Yes (1)No (2)No (5)	33. Did your child receive all the dental care that he or she needed?Yes (skip to question 35) (1)No (2)Don't know (5)
28. Have you needed additional income to cover your child's medical expenses? Yes (1)No (2)Don't know (5) 29. Have you or other family members stopped working because of your child's health conditions? Yes (1)No (2)Don't know (5) 30. Have you or other family members refrained from changing jobs because of your child's health insurance status? Yes (1)No (2)Don't know (5)	34. If no, why did your child not get the dental care he or she needed? Check all that apply. Cost too much (1) Health plan problem (2) Not available in our area (3) Transportation problem (4) Other (6) Don't know (5) 35. During the past 12 months, was there a time when your child needed mental health services? Yes (1) No (skip to question 38) (2) Don't know (skip to question 38) (5) 36. Did your child receive all the mental health services that he or she needed? Yes (skip to question 38) (1) No (2) Don't know (5)
Community-Based Service Systems 31. Thinking about the services your child needs, are those services organized in a way that makes them easy to use? Never (1)Sometimes (2)Usually (3)Always (4)	37. If no, why did your child not get the mental health service he or she needed? Check all that apply. Cost too much (1) Health plan problem (2) Not available in our area (3) Transportation problem (4) Other (6) Don't know (5)

Appendix 2: Survey

when your child needed substance abuse	40. If no, why did your child not get the substance abuse service he or she needed? Check all that apply. Cost too much (1) Health plan problem (2) Not available in our area (3) Transportation problem (4) Other (6) Don't Know (5)			
Transition to A (Respond only if your chil		_	or older	.)
` ' ' '		<u> </u>		,
Now we would like to ask about transition planning for adult life, adult health care, work, and independence. Please check the box that best reflects your experience.	(1	es)	No (2)	Don't Know (5)
41. If your child is 12 years or older, has your child's doctor other health care provider talked with you or your child about how his/her health care needs might change when he/she becomes an adult?	or			
42. Has a plan for addressing these changing needs been developed with the doctor or other health care provider(s)?				
43. Has your child's doctor or other health care provider discussed having your child eventually see a doctor who treats adults?				
44. Has your child received any vocational or career training to help him/her prepare for a job when he/she becomes an adult?				
Demographic Information for Statistical Purposes only Again, this survey is anonymous and confidential. No names or individual identification is used. The survey will only compile data based on aggregate numbers and percentages that result from the survey. We would like to gather some demographic data reflecting the families surveyed. Please take an extra few moments to complete this final part of the survey. Thank you.	need 46. I	ls you What i Bel Cai Cho	r child ma s your co knap rroll eshire	child with special health care arsMonths lle (1) or female (2)? unty of residence? (1) (2) (3) (4) (5)

Appen	dix	2:	Sur	vey
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Merrimack(7)	
Rockingham (8)	51. What is your household income:
Sullivan (9)	\$
Strafford (10)	Do not know: (5)
	Decline to answer: (9)
48. What is the race/ethnicity of your child?	,
.	52. How many children <i>under</i> 18 are in your household?
49. What is the primary language spoken at	
home?	53. How many adults <i>over</i> 18 are in your household?
50. How long has your child had his or her primary condition? Years Months	

END OF SURVEY Please return completed survey as soon as possible in the envelope provided.